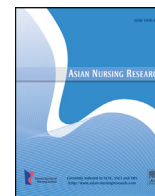


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## Research Article

## Experiences of Caregivers in Healthcare for and Social Support of HIV Positive Children Attending Schools in Bangkok

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## SUMMARY

**Purpose:** The study was conducted to explore caregivers' experiences and perceptions of barriers to their children receiving appropriate healthcare and support at schools in Thailand.**Method:** A qualitative narrative study was conducted to achieve the aim stated above. Twenty caregivers of children living with HIV/AIDS attending schools in Bangkok were interviewed in depth. The interviews were audiotaped, transcribed and analyzed using narrative analysis.**Results:** The analysis indicated that caregivers fear discrimination, suffer from stigma and most do not reveal their child's HIV status to schools. Obstacles to children living with HIV/AIDS getting appropriate care and support in schools are persistent. Caregivers need to collaborate with the public health sector to provide HIV education and support for themselves and for teachers; community nurses would be well placed to provide this.**Conclusion:** Our findings can inform the design of systems for educational and social support alongside adequate healthcare for children living with HIV/AIDS attending school. The Thai government needs to establish collaboration between the educational and health sectors to reduce the stigma of HIV, promote acceptance and provide support.

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## Introduction

In 2013, it is estimated that 610,000 people in Thailand are living with HIV, and 23,000 people have died from AIDS-related illnesses in the past 12 months (UNAIDS, 2013). The population of HIV positive children under the age of 15 in Thailand is estimated to be between 12,000 and 17,000 with approximately 4,200 new infections occurring annually (UNAIDS/WHO, 2009; UNICEF, Thailand, 2010). Although the Thai government has launched a healthcare program providing anti-retroviral therapy for pregnant women to prevent mother-to-child transmission of HIV, the prevalence of children born with HIV is still about 3% (UNICEF, Thailand). Healthcare programs focused on reducing the number of HIV-infected children and providing long-term care and educational support for existing children living with HIV/AIDS may be

overlooked by the government despite a much better prognosis with the increased availability of antiretroviral treatment. The Universal Declaration of Human Rights states that all children have the right to survival, protection, development and participation to enable them to successfully achieve the "goals of childhood" (United Nations, 2003). Children living with HIV/AIDS should have equal access to education, as well as access to treatment and care including attention to their special needs, all of which would enhance their physical and emotional well-being and their social and intellectual development (UNESCO, 2000; United Nations, 2013).

Several reports about HIV/AIDS in Thailand have shown that children living with HIV/AIDS are discriminated against and often rejected from school because the parents of other children fear HIV transmission to their own children (Klunklin & Greenwood, 2006; Thailand Division of Communicable Disease Control, 2003). Caregivers, whether or not HIV-positive themselves, suffer from discrimination and as a result families may keep a child's HIV infection a secret (Demmer, 2011). In areas where there are large numbers of HIV/AIDS infected people, other members of the community may fear becoming infected. As a result, some caregivers who have sought help have been rejected or abandoned,

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even by family members, when they disclose their children's illness. Consequently, they receive little support from their communities (Lyons, 2006; Yoktri, 1999). Caregivers and children with HIV/AIDS have experienced such discrimination and hostility from teachers that children had been withdrawn from school (Thampanichwat, 2008). Previous studies of children living with HIV/AIDS in Asia (including Thailand) have reported that the three main impacts of HIV infection are loss of social and family support; stigma and discrimination; and decreased access to education, healthcare, and social services (Wijngaarden, 2001; Wijngaarden & Shaeffer, 2005).

Schools could act as center-points for comprehensive community responses to HIV/AIDS as they are the ideal places to bring teachers, caregivers and others together to help support vulnerable children in a coordinated and effective way (UNAIDS, 2003). However, although the Ministry of Education in Thailand has established regulations to promote access to free education for all children and to provide support to disadvantaged children (Thailand Office of the National Education Commission, 1999), there is very little evidence that the educational system in fact has provided adequate support to children living with HIV/AIDS. In addition, we know very little about what caregivers experience when their children with HIV go to public schools, how caregivers describe their experiences of the healthcare and support and what help they need. Healthcare providers and policy makers need to understand the challenges and obstacles that caregivers experience while looking after school age children with HIV/AIDS and how their children can access free education and elicit support. Thus, the approach of this study, underpinned with principles of narrative analysis, can assist healthcare providers and policy makers to more deeply understand the situation of caregivers of children with HIV/AIDS and so act to improve health care and support for their children.

### *Aims of study*

This study aims to describe the experiences and difficulties experienced by caregivers of children with HIV/AIDS attending public schools. Narratives of participants provide important information to guide educational organizations in offering appropriate healthcare and support to children with HIV/AIDS in schools (Sakaly, 2003). The research questions were: (a) what do caregivers experience when their children with HIV go to public schools? (b) How do they describe their experiences of the healthcare and support that is made available to them?

## **Methods**

### *Study design*

Qualitative narrative method was used to explore and then depict what happened when family caregivers sent their children to schools. Qualitative study of subjective experiences and common dialogue of caregivers' story-telling was appropriate in this study because it captured with authenticity the opinions and responses of the participants (Atkinson, 2007). Their narratives also described experiences of family caregivers who had themselves provided care for children with HIV/AIDS and the obstacles they faced when they voiced their need for healthcare and support.

### *Setting and samples*

This study took place in Bangkok, the capital of Thailand with a total population of 8.25 million based on the 2010 Census. In addition, the number of people living with HIV was 56,717

(Thailand Division of AIDS, TB and STIs, Health Department, 2011). We recruited a purposive sample of 20 family caregivers of children with HIV/AIDS who joined the activities with HIV/AIDS clubs and organizations in Bangkok. The leaders of HIV clubs and organization were instrumental in providing assistance and advice to low-income caregivers living in communities in inner urban and sub-urban areas of Bangkok. These leaders also referred potential, appropriate participants to the investigators. The criteria for selection required participants to be biological mothers or fathers (or other male or female relatives) who acted as primary caregivers of children with HIV/AIDS. Participants had to be taking care of a child who had attended school for at least 6 months. Participants had to be Thai speakers and were sufficiently healthy to participate in the activities of the HIV clubs.

### *Data collection*

The study was conducted over 18 months from January 2008 to June 2009. The 20 family caregivers of children with HIV/AIDS were introduced to us by an HIV/AIDS organization and invited to participate in the study. In-depth interviews of the 20 participants were conducted in private rooms in their homes. Using their previous related experience, the authors developed a semi-structured series of open-ended questions that allowed them to lead participants into an in-depth interview as follows: Please tell me about your child's illness. How does the teacher take care of your child when he or she gets sick? Do you disclose your child's HIV status to the teachers? Why (or why not)? How did you feel about the teacher's response when he/she knew your child's status? Tell me about a recent bad day in caring for your child when he/she was going to school. Follow-up questions were created to facilitate an in-depth interview with empathic listening and to investigate further the caregivers' experiences in caring for their children. Each interview was tape-recorded and lasted 50–60 minutes. Triangulation technique was used after each interview by means of discussion with peers, and by participants' confirmation. We analyzed the narrative data confirming our understanding by asking comprehensible questions, re-reading the narrative accounts in conjunction with the questions, articulating more explicit questions based on these close readings and creating codes that reflected the narratives discerned in the interviews. After interviewing 20 participants, no new codes or additional data emerged from the narratives. Thus, the data collection was judged to be saturated.

### *Data analysis*

Data were transcribed verbatim with all interview data reconfirmed by the participants. The interviews were conducted and analyzed in Thai language and only the excerpts referred to in the study were translated into English. The accuracy of the English language translation was confirmed by an expert from the Faculty of Arts at Chulalongkorn University. The translation of the excerpts was checked by the authors for accuracy and consistency. Interview data were analyzed using a thematic analysis with multi-staged analysis technique (Riessman, 2008; Stevens 1993; Stevens & Doerr 1997). A multi-staged narrative analysis was devised based on synthesis and extension of narrative techniques articulated by the investigator and experts. These stages were as follows: (a) demarcation of the boundaries of each story in the interview and group transcripts, (b) analysis of story content and context, with attention paid in each case, to obstacles and needs for support and care for children with HIV/AIDS in schools, (c) searching for similarities and differences in children with HIV/AIDS' care and support among the various participants, and (d) the experiences of obstacles as described by all 20 participants when matched and

contrasted. The aims at this point were to search for agreements and distinctions in experiences of caregivers across individuals and to distinguish patterns in story plots and identify main themes (Riessman). Finally, we created 64 codes along with subcategories consistent with this study's aims. We conducted cross checking of the findings with the expert's consensus and received feedback from the participants.

#### Ethical consideration

The study received approval from the ethics committee of the Thai Red Cross College of Nursing. Letters were distributed through HIV/AIDS organization in the community to invite parents and family caregivers to participate in the project. We obtained both written and verbal consent from participants at the first interview in their homes. All were informed of the objectives of the study and the steps involved in data collection. They were assured any data elicited from them would be kept strictly confidential and protected by the use of codes and anonymity.

#### Results

The participants were 14 parents and 6 family caregivers, a group which included 18 females and 2 males living in Bangkok. Seventy percent of them were casual workers, 20% were long-term employees and 10% were out of work. They reported monthly incomes ranging from 2,000 (60 USD) to 6,000 Baht (190 USD) a month all of which were manifestly inadequate and below the poverty line for income in Thailand. Some of them received support from their relatives and some have gone into debt. There were 12 single mothers, 2 single fathers, and 6 grandmothers and their ages ranged from 35 to 72 years. They were taking care of children with HIV/AIDS who ranged in age from 7 to 14 years. Ten of the children were girls and 10 were boys—all attending public primary schools and secondary schools near their homes. Those who lived with grandmothers had lost their parents to AIDS. All were receiving antiretroviral treatment. Six of them had AIDS-related symptoms and had had 1–5 hospitalizations and 14 of them were in good health. The demographics of the 20 participant caregivers are summarized in Table 1.

Three main themes became apparent during the analysis: (a) inadequate resources in school for children living with HIV/AIDS, (b) discrimination in the learning context and social stigma in the community of the school, and (c) caregivers' voices for improved care and support for children with HIV/AIDS in schools.

**Table 1** Demographic Characteristic of Caregivers (N = 20).

Characteristic	n (%)
Gender	
Female	18 (90.0)
Male	2 (10.0)
Relationship to child	
Single mother	12 (60.0)
Single father	2 (10.0)
Grandmother	6 (30.0)
Occupation	
Casual worker	14 (70.0)
Long term employee	2 (10.0)
Out of work	4 (20.0)
Education of caregivers	
Primary school	8 (40.0)
Secondary school	6 (30.0)
High school	6 (30.0)
Age of caregivers (yr)	Range 35–72, M = 46.8
Age of children (yr)	Range 7–14, M = 8.4
Household income	Range 60 USD–190 USD, Median = 145 USD

#### Inadequate resources in schools for children living with HIV/AIDS

The results of study reflected limitations of the educational system in terms of human resources which were divided into two subthemes:

##### Teachers' lack of adequate knowledge of AIDS

All the children in this study were enrolled in public schools approved by the government and where no health facilities were provided. All family caregivers mentioned the problem of teachers who had inadequate HIV/AIDS knowledge to effectively manage chronically ill children especially those HIV infected. In addition, they were not sure that teachers would have knowledge of HIV/AIDS. There was a generally expressed fear that teachers were often misinformed about how the virus is contracted and so liable to mishandle situations where children with HIV/AIDS were mixing with other children.

Now some teachers are still afraid of getting AIDS from taking care of children who have skin rashes because they lack adequate knowledge of AIDS related symptoms. Even though they know that AIDS is not transmitted easily, they are afraid to care for children who have AIDS related symptoms... My granddaughter had a lot of skin rashes on her arms and legs... Her teacher suspected and ask my granddaughter. She told the teacher that she was sick... So, the teacher told her not to come to school because she would spread AIDS to her friends... so, I moved my granddaughter to the countryside. (case 12)

##### Lack of appropriate health personnel at school

Most caregivers also mentioned the lack of healthcare providers to take care of children living with HIV/AIDS at schools because they knew that there were neither nurses nor physicians available to serve the schools. The public schools cannot employ nurses or health personnel to take care of children in schools because they do not have the funding. The teachers who teach health education are usually made responsible for caring of children who become ill at school. Caregivers worried about the safety of their children when their children had health problems, because they perceived that the teacher could not take care of their children effectively. One mother said the following:

I saw many teachers who did so many activities at the school. They had no time to look after sick children, especially children with HIV/AIDS. When I learned that community health nurses would come to the school to give children vaccinations, I always let my daughter drop out of the school on that day. I was afraid that she would get ill (if she had vaccination). (case 6)

##### Discrimination in learning context and social stigma in school community

Most caregivers did not disclose their children's HIV status when they went to school. They perceived difficulty in accessing education and lack of support for their children in terms of social stigma and experiencing suffering.

##### Fear of discrimination and social rejection

None of the family caregivers disclosed their children's HIV status to schools because of previous bad experiences and their fear of discrimination and social rejection. Some caregivers had bad experiences and suffered when some teachers discriminated against children with HIV because their children were AIDS

stigmatized and rejected from schools. It was common to confuse AIDS and HIV for teachers. Some teachers still had misconceptions about HIV/AIDS and thought that children with HIV would have short lives and were poor learners. One caregiver described the impact of the disclosure of her grandson's HIV status as follows:

I moved my grandson to a new school, and I have never told any teacher that he is an HIV infected child. I don't trust them because they have prejudice or bias against children with HIV... I had a bad experience when I disclosed his HIV status at the old school. I told his teacher that his parents died because AIDS. So, his teacher knew about his infection status, and I suffered because his teacher did not keep the important secret of the child and family. So, all teachers at the school perceived that he had AIDS ... (but her grandson was HIV infected child). The principal said that I should move my grandson to a new school because he would spread AIDS to other children... He said children with HIV did not need to study anymore because their lives were going to be cut short and their IQ was also very low... My grandson was very sad because he was rejected from another school. He always keeps his secret and he is not joyful like other children. (Case 14)

#### *Experiencing difficulties in accessing educational support*

Poorer families struggled to cope with the additional items needed for their children at school but fear of discrimination meant they would not disclose the child's status and hence could not receive adequate social and educational support. They tried to find healthcare and educational funds for the children outside school. One grandmother explained as follows:

I have to take care of three orphans, and one of them is HIV infected. All three of them need educational support. Although the government provides free education for all children, it does not include other expenses related to studying. Although there are some scholarships for poor pupils, I have not disclosed my grandson's health status to his teacher because I am scared that he would be discriminated against by his teachers and friends. I have to pay for books, internet access, and many other things, which is about 4,000 baht (31.2 USD) per child. I am very stressed and sad because I have no money... I have lost my job and cannot find money on time... I need funding for the children's education. Giving them proper education as well as best treatment and care is the most crucial issue... (Case 13)

#### *Caregivers' voices for improved care and support for children with HIV/AIDS in schools*

Four main needs were identified by participants in healthcare and social support of children living with HIV/AIDS when attending schools because supplying caregivers' needs would solve the problems of social stigma and discrimination and provide healthcare and social support for their children.

#### *Need for social acceptance*

Although the government launched the campaign of community support for people living with HIV/AIDS, family caregivers perceived that children with HIV were not accepted by society. Family caregivers stated that the issue of discrimination against HIV/AIDS patients in society as a whole and in schools needs to be addressed. Their needs reflected the government to seriously promote social acceptance for children living with HIV/AIDS to equally access to school like other children. This sentiment was expressed by one caregiver:

Every school should accept HIV infected children and allow them to study with other children. I think a great concern is social discrimination against people with HIV/AIDS. There is a need to find the solution to this social problem. The government should educate people in the community and make them understand what AIDS is. The parents of other children should not reject children with AIDS. Instead, they should sympathize with them... (Case 10)

#### *Need for more knowledge and skill*

Moreover, caregivers mentioned inadequate knowledge for taking care of children with HIV/AIDS who often needed complicated care. This required updated knowledge from, and consultation with trusted health professionals. One mother who had problems with caring for a child with symptomatic AIDS shared her experiences:

I suffered greatly when my child had a high fever. I tried to give him medicine to reduce his fever, but I was very afraid that the medicine would make him worse... I spent a lot of time taking him to the ER, and I did not receive any health information from nurses. I needed to know a lot of information about how to take care of my sick child... If I can consult a nurse whom I trust by phone, it would be better... I think if nurses give us health education or workshops on how to take care of sick children, I could manage my sick child much more effectively... (case 8)

#### *Collaboration and networking with health professionals*

All family caregivers perceived that teachers lacked the knowledge to care for children with HIV. There were neither health professionals nor adequate medical supplies in schools. Thus, they suggested that schools should have a care network involving nurses from institutions near schools. Some caregivers who worked as health volunteers in the community suggested a need for health specialists who could come to support teachers and also organize HIV/AIDS training programs and care for children. One participant explained as follows:

If possible, all schools should have nurses or medical doctors because they can provide direct care for sick children. The doctors or the nurses who know our children should coordinate with the school nurse or health education teachers to take care of HIV infected children and keep their HIV status secret... Schools should have a care network involving nurses from institutions near schools. In particular, nurse-educators should come to schools to provide health educational support for teachers and to arrange medical supplies such as first-aid boxes, simple antiseptic solution, rubber gloves, and home medication for the teacher who is in charge of the infirmary... (case 6)

#### *Long term care and support from government*

All caregivers expressed their love for their children and many were concerned about their own health problems because of their HIV status. Some older caregivers have chronic illness and fear for their children's future. They wanted their children to have a certain future with social support. A poor 72-year-old participant who earned about 100–150 baht (3.1–4.8 USD) per day said the following:

I may not outlive my grandson because I am very old and have multiple illnesses. I need him to grow up and be able to stand on his own feet. I want long run free education and support from the government until he grows up. I hope that he can earn money by himself. If he cannot have higher education, there should be occupational training and help for him to earn money



by himself. He should be given free anti-viral drugs for the rest of his life. (case 18)

## Discussion

The results of this study identify some challenges and obstacles to supporting children living with HIV/AIDS attending school in Bangkok. Particular problems were the lack of trained personnel in schools to provide basic medical care, lack of updated HIV knowledge and skills for teachers, financial difficulties for families with children with HIV/AIDS and the persistent social stigma of HIV affecting family caregivers. Stigma, poverty and minimal emotional or material support were also found to be problems in South African families caring for children with HIV/AIDS and were perceived to compromise the health of the child (Demmer, 2011). All children should have equal rights to attend school and receive high-quality educational services and support regardless of their health condition or infection status (Kahssay & Oakley, 1999; Rifkin, 2003). This present study has shown that, according to this group of caregivers of children with HIV/AIDS, in practice this is not the case.

One of the big issues is HIV-related stigma and discrimination. This has been widely reported previously both in resource-limited (Cluver & Gardner, 2007; Demmer, 2011; Devine, 2001; Groce, 2004; Thampanichwat, 2008; Wijngaarden, 2001; Zhao et al., 2010) and high-income settings (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). In this study most caregivers had not told the school of the child's HIV status and this lack of open dialogue between families and schools about HIV can mean that children do not receive appropriate support or understanding at school and can miss out on necessary medical care. Thus, they may be taken out of school on vaccination days, may fear or delay seeking medical care because it may lead to the discovery of their HIV status by the school. This may greatly burden a child in keeping such a "secret". Yet when families have been open about the HIV diagnosis they have suffered from such negative reactions from teachers and other caregivers or children that they felt compelled to remove the child from school. This is consistent with results from other studies (Klunklin & Greenwood, 2006; Lewis, 2001; Thailand Division of Communicable Disease Control, 2003; Thampanichwat, 2008).

Family caregivers felt that both teachers' HIV knowledge and skills for taking care of children with HIV/AIDS were inadequate, which is consistent with the other studies showing that teachers lacked knowledge of HIV and skill to take care of children with HIV in schools (Sriyaporn et al., 2004). Better HIV knowledge for teachers and caregivers has been shown to be associated with less stigma (Zhao et al., 2011). A study of primary schoolchildren in Thailand showed that educating both teachers and caregivers about HIV decreased stigma and discrimination (Ishikawa, Pridmore, Carr-Hill, & Chaimuangdee, 2011). Policy makers, especially those in educational and health sectors need to keep the public updated on HIV knowledge to help decrease stigma and discrimination for all affected by HIV. People still have many misconceptions about HIV transmission and about its prognosis, which negatively affect their attitudes to children living with HIV/AIDS (Ishikawa et al., 2011; Zhao et al.).

This present study demonstrated the lack of adequately trained staff in schools (either of a nurse or specially trained teacher) to provide appropriate healthcare to children with HIV/AIDS when needed. To provide quality care for chronically ill children in schools, collaboration between the public health and educational sectors including practical strategic planning is required. The ministry of education should provide health care provision for sick children, particularly children with HIV/AIDS in schools in terms of

setting aside sufficient medical supplies in an infirmary with a physician or a nurse who can provide direct care for children with HIV/AIDS. Health professionals including nurses should be able to act as consultants for teachers and family caregivers in providing health information and care for children with a chronic illness (Sakalys, 2003; UNICEF, UNAIDS, WHO, & UNFPA, 2010). Community nurses should maintain appropriate communication with teachers in schools to facilitate the education of children in their care (Conway, 2005; UNESCO, 2008).

As suggested by caregivers in this study, teachers, family caregivers, and school nurses must all be armed with updated knowledge of HIV and infectious diseases, management of medication (and its side effects), together with the skills to meet the potential long-term needs of the infected children. All schools should have health personnel such as nurses and teachers who have the counseling skill to approach family caregivers and children with HIV/AIDS. Continuity of care between the healthcare setting in home and school should be provided with confidentiality about HIV status and disclosure given only with the consent of the caregivers and age-appropriate assent of the children (Conway, 2005).

Caregivers in this study play important roles but as was found in a study in Africa (Kuo & Operario, 2010), they suffer a high level of stress related to poverty, stigma, social isolation, and have to confront many problems caused by the needs of the infected child and the caregivers' own health issues. Poor health in the caregiver is a strong indicator of poor health of the child infected with HIV. Health needs of caregivers need to be supplied by health providers so that both the caregiver and the child can remain in good health (Thielman, Ostermann, Whetten, Whetten, & O'Donnell, 2012). Difficulties in accessing health care and support found in this study were similar to those found in Uganda (Kipp, Satzinger, Alibhai, & Rubaale, 2010). All family caregivers had low income and were often unemployed. Thus, strategies should be put in place to help support families. In addition, policy makers should raise awareness and provide long-term funding for free education together with offering medical and social welfare which are essential for children living with HIV/AIDS and for their caregivers (Conway, 2005; UNICEF, UNAIDS, WHO & UNFPA, 2010).

Even though this study included a small number of participants, we argue that acceptable saturation was achieved. The participants are extremely valuable and represent an adequate number for a group of caregivers that is difficult to access because they deliberately conceal themselves (Baker & Edwards, 2012). There was a representative sample of experiences and attitudes of family caregivers living in the city and the sample reflects the circumstances of such a hidden population in Thai society with lack of coordination, or between health and education sectors and poor contacts between these sectors and the population of caregivers the children living with HIV/AIDS whom they support. The context of this study may limit its reproducibility to other regions of the world with low prevalence of HIV and different provision of healthcare and social support in schools. However, many of our findings are consistent with those from other studies, particularly from Africa (Cluver & Gardner, 2007; Demmer, 2011; Kipp et al., 2010; Whetten et al., 2008).

## Conclusion

Our findings can inform the design of systems for educational and social support alongside adequate healthcare for children with HIV/AIDS attending school. Both health and education policies should involve the promotion of cooperation between healthcare providers, family caregivers, and teachers and include ongoing education for teachers and for family caregivers. Governments need to continue to address HIV stigma by using widespread educational

campaigns to accept and advocate for children with HIV/AIDS in schools and the community at large. We recommend that further studies on capacity building of caregivers and teachers should be conducted to improve their knowledge and skill of care for children with HIV/AIDS. Guidelines for the care of children with HIV/AIDS should be developed with practical information on appropriate methods so that schools can provide a suitable environment and emotional support for children with HIV/AIDS and their caregivers.

### Conflict of interest

There are no conflicts of interest concerning this manuscript.

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